

Coalition-In-Progress: Found Poetry Through Phone Calls with People Labelled/With Intellectual Disability During the COVID-19 Pandemic

by Erin Kuri, Antoinette, A. K., Bill Chase, Cindy Scott, Doreen Kalifer, Harold George Dougall, Kevin John Head, Marie, Nicholas Herd, P. A. I., P. S., R., Sean Simone, Chelsea Temple Jones and Ann Fudge Schormans | Issue 11.2 (Fall 2022), Crip Pandemic Life: A Tapestry

ABSTRACT For institutional survivors and their younger peers labelled/with intellectual disability, the COVID-19 pandemic and its related lockdowns carry over past experiences under government-directed isolation and mandatory medical interventions. The sudden convergence of past and present necropolitical ableism in labeled persons' lives colours this crisis, as we—a group of survivors, younger labeled people (who have not lived in institutions), and researcher/allies—attempt to simply stay in touch amid digital divides that cut off our once vibrant, interdependent in-person activities. No longer able to gather, and with limited Internet (or no) access, we resist social abandonment through phone calls. During phone conversations we discuss the affective contours of this time: grief over the past, loss of agency, restrictive rules in group homes, the dynamics of protest, fear sparked by public health orders, and a mix of anxiety and hope about the future. Taking this telephone-based dialogue as evidence of our lives in these times, we present a brief body of collectively written found poetry, a form of poetic inquiry composed of phone call snippets. This piece, coauthored by twenty members of the “DiStory: Disability Then and Now” project in Toronto, Canada, offers a snapshot of coalition-in-process, keeping in touch amid a crisis that threatens our togetherness and—for some more than others—our lives. Following Braidotti, we couch this found poetry in a brief commentary on our slow, in-progress attempt to “co-construct a different platform of becoming” with one another amid a divergence of historical and contemporary inequities.

KEYWORDS disability, justice, poetry, COVID-19, ableism

Note: Each of the authors of this paper made their own decision as to whether to use their full name, first name only, or initials.

Introduction

This found poetry offers snapshots of the ways in which a group of individuals labelled/with intellectual disabilities—some of whom identify as institutional survivors and some identifying as members of a younger generation of people who have not lived in institutions—and researcher/allies, keep in touch via phone calls during a global pandemic and its subsequent lockdowns in Toronto, Canada. This collaborative writing speaks to some of the complex affective ways that we, as a group, experience coalition-building-in-progress in ableist, high tech cultures and under lockdown.¹ While digital mediation was a viable coalition-building tool for some folks at the height of the COVID-19 pandemic, many people in our group live without access to digital worlds. For us, coalition-building is an ongoing process operating on a low-tech plane; we connect through telephone calls. The writing below is grouped through four themes that emerged in our found poetry writing process: attempts to simply stay in touch amid digital divides during especially isolating times, resistance to social abandonment, the uncanny experience of a sudden convergence of past and present necropolitical ableism, and an attempt to “co-construct different platforms of becoming.”² Taking this telephone-based dialogue as “evidence” of our lives in these times that might be, and make us, “recognizable” to one another,³ the poetry below chronicles the “DiStory” group’s coalition-in-progress efforts to keep in touch amid a crisis that threatens our together-ness and—for some more than others—our lives.

Background

Our group, called “DiStory” (a mash-up of the words “disability,” “story,” and “history”) took shape through a series of in-person meet-ups beginning in 2017. Participating in these gatherings were coresearchers labelled/with intellectual disabilities, non-labelled academic and community-based coresearchers and research assistants, and non-labelled arts facilitators.⁴ The focus was on learning from people labelled/with intellectual disabilities, including survivors of Ontario’s Regional Centres—large-scale provincial institutions, the last of which closed in 2009 but whose legacy of institutionalized care, discrimination, and ableism live on in the day-to-day experiences of both survivors and younger people labelled/with intellectual disabilities.⁵ This learning informed the collaborative determination of the purpose of our project: our collective creation of learning materials for post-secondary students. This decision reflected labelled coresearchers’ concerns that the day-to-day experiences, needs, and desires of people labelled/with intellectual disabilities

remain largely invisible to most people. Combined with their worry that the closure of Ontario's large-scale institutions was leading to a misguided belief that everything was now "OK," and that discrimination, exclusion, and violence were no longer an issue for people labelled/with intellectual disabilities, they turned their sights towards the education of young people who they understood to have the power to shape a better future.

The COVID-19 pandemic called on us to reimagine our engagement with each other at the onset of regional lockdowns. Although it is widely understood that lockdowns are designed to keep us safe from contracting coronavirus, the abrupt halt to in-person gatherings (that once served as a lifeline for community engagement with the arts, activism, and other forms of organizing) felt alarmingly familiar to many labelled "DiStory" members: social restrictions starkly echoed the trauma of past experiences in institutionalization designed with eugenic thought to separate the populous from a perceived threat of disability. And, problematically, for many "DiStory" group members living without access to Internet or communication technologies such as computers, government-ordered social cut-offs that began in early 2020 and continue today cannot be supplemented through digital communications and remain isolating.

Process and Method

To resist isolation, we connect through telephone conversations. Though it may take a few tries, it is possible to reach "DiStory" members via phone calls if they are living alone or in group homes and other shared living spaces. For all "DiStory" members, maintaining our connections in conditions of (often extreme) isolation is essential. Both labelled and non-labelled coresearchers also desire to keep the project moving. Being less able to adapt previously planned project activities to this new way of working, together we turned our attention to the necessity of speaking out and against the invisibility of people labelled/with intellectual disabilities in pandemic planning and responses.

At two different points in time (summer 2020 and fall 2021) Erin Kuri, a non-labelled coauthor, engaged each labelled coresearcher in audio-recorded conversations about their pandemic experiences, thoughts, worries, fears, and hopes; about what they have been doing individually and collectively; and about what they want non-labelled others—especially governments—to know, and consequently, to do.

Two years and a great many phone calls later, coauthors of this paper (a mix of labelled and non-labelled coresearchers) scribed a series of found poems based on transcripts from these audio-recorded conversations.

Working with all the transcripts, Kuri identified four emergent themes and created a document linking themes with transcript fragments reflective of each theme. Engaging then in numerous one-on-one telephone conversations with labelled co-authors, the meanings of and connections between fragments became clear. Non-labelled co-authors (Kuri, Fudge Schormans, Jones) collaborated to format each poem to reflect these meanings and connections, and the emotions within each, to reveal labelled coauthors' lived experience,⁶ with Kuri sharing these constructions with labelled co-authors and inviting feedback via phone calls. Poems were reconstructed in response to feedback and shared once again. Through this process, fragments were care-fully assembled into the poems we share here. The poems then are the words of labelled group members. Jointly crafted by labelled and non-labelled coauthors, each poem is composed of the words of multiple labelled group members, with some degree of influence from non-labelled coauthors—an interlacing that draws out the affective contours of the conversations and the fragments.

Our found poetry is influenced by postmodern feminist approaches to knowledge building that value intersectionality, collaborative egalitarian ways of working, ethics of care, and reflexive praxis. These values guided decisions made with respect to processes and outcomes of the research. Throughout the "Distory" project, Kuri had been engaged in regular communication with labelled coauthors, forming familiar working relationships built on respect, empathy, trust, reliability, and mutual passion towards social justice aims of the group. These relational ties were foundational to engaging in our found poetry research methodology, supporting labelled authors to feel more comfortable sharing their perspectives.

While such relationships are necessary for this kind of collaborative work, our attunement and care to relational dynamics included recognition of how labelled authors may rely more on non-labelled authors. Labelled authors relied on the relationship with Kuri to be able to participate in the project. As well, they relied on non-labelled authors to represent their experiences and perspectives in a way that avoided pathologizing, victimizing, or infantilizing them. For non-labelled authors, a great deal of trust therefore is placed in their hands to prioritize the best interests of those most marginalized in the group. As a means of attuning to matters of dependency, Kuri engaged in practices of ongoing written and verbal informed consent. She paid particular attention to ensuring, as much as possible, that labelled group members understood that their relationship with her and their participation in the project would not be negatively impacted by any dissenting opinions they had about the writing or decisions they made with respect to inclusions or exclusions of any part of their transcript material. Overall, when Kuri shared the constructed poems with labelled authors, they articulated appreciation for how their words and ideas were included, some added suggestions, and all expressed pleasure with the final poems.

We draw on found poetry as a form of research—as both representation and analysis, a means by which to learn and ethically re-present labelled co-authors' experiences and thoughts.⁷ In consideration of their marginalization as “knowers,” we also understand found poetry research as pushing back, as resistance to their long-standing invisibility and silencing—an invisibility that has had significant consequences in terms of pandemic planning and responses.⁸

As a form of poetic inquiry, the research method of found poetry involves one or more researchers creating poetry in a collaborative and relational manner by selecting exact words, or phrases from materials such as interview transcripts, field notes, email discourse, texts or literature. These elements are then cut and pasted together, attending to spacing and line breaks, revealing the essence of labelled coauthors' lived experience. Found poetry is an accessible way of imaginatively and intertextually reconstructing already-existing texts which, in our case, were phone call transcripts.⁹ Although the term “found” may imply lack of intention, accountability of researchers to those they collaborate with is central to interpretively transforming words and phrases located within the transcripts into poetic form. Through this transformative and collaborative process, lived experience of those most marginalized may be holistically represented with an aim to preserve and evoke affect. The emphasis on affect makes vicarious participation (showing instead of simply telling) accessible to a broad audience, thereby evoking empathy and creating potential for learning and positive change. Through collaborative back-and-forth exchanges, striking passages were selected and clustered into thematic groups. Essential words, phrases, pauses and silences from transcripts were then reconstructed into what Rosi Braidotti terms “fragments of meditation upon the sorrowful present” of the pandemic, upon its roots in the past, and worries—and hopes—for the future.¹⁰ The affective contours of these found poems based on phone conversations—that is, the emotive and political intensities colouring our chats that make us *feel* something¹¹—point to grief over the past, loss of agency, restrictive rules in group homes, the dynamics of protest, fear sparked by public health orders, and a mix of anxiety and hope about the future. Found poetry's capacity for communicating these affects and expanding perspectives is always partial and in-progress because they are open to interpretation, and thereby also open to misinterpretation.¹² As Braidotti points out in her discussion of ethical inquiry amid crises, “Words, in so many ways, falter and fail.”¹³ Yet, these poems are a bricolage of our attempts to share a complex, sometimes un-articulate evidence of becoming coalition-in-progress in pandemic times.

Reflection

Our poems explain why we think of ourselves as becoming coalition-in-progress. Early on in our work together, in-person pre-pandemic meetups supported coalition-building amongst “DiStory” group members, an emerging intergenerational coalition of individuals with and without the label of “intellectual disability,” and/or other disability labels or identifications. The enforced shift to virtual engagement at the onset of COVID-19 worked to exclude many “DiStory” members, interrupting project work of engagement, sharing, and learning—of becoming coalition. Here, following Braidotti, we recognize that we are going through an “extraordinary period” of high-tech cognitive capitalism that contributes to pandemic conditions in the first place.¹⁴ The increased use of technology and digital interventions that supported many groups at the height of COVID-19’s impact was inaccessible to us. For some folks labelled/with intellectual disabilities, access to high-tech connectivity is impossible and this exclusion represents one characteristic of what Shayda Kafai terms nondisabled supremacy.¹⁵ Excluded, ignored, not-considered in pandemic planning and responses, “DiStory” group members labelled/with intellectual disabilities are those about whom Patty Berne voices concern, over when she explains that “during the pandemic, eugenic practices increased and no alarms were sounded.”¹⁶ Sidelined at the low-tech side of a complex digital divide during a time of crisis, our coalition-building remains in progress. In this context, the telephone comes to signify possibility, an unanticipated platform by which to connect, carry on with the work. Co-constructing found poetry—via telephone—further facilitates becoming coalition. While in many ways a lifeline, these platforms cannot replicate that which was possible in-person. We are not able to launch more radical coalition-building—cross disability and/or cross-movement coalition building—or to more actively advocate for change because, as the poems below demonstrate, we are preoccupied with oppression and survival.

Between the lines of these poems is evidence of necropolitical, trauma-inducing policies that threaten the lives of our group members, including the pairing of Medical Assistance in Dying (MAiD) legislation in Canada known as Bill C-7¹⁷ and clinical triage protocols that, as disabled self-advocates argue, deprioritizes disabled people.¹⁸ Amid this necropolitical context, perhaps it is fair to say that we are “in-progress” rather than a more sharply defined coalition because some more than others in the “DiStory” group are still grappling with threats to their lives brought on by COVID-19 policy responses.

In other words, these poems are not intended to symbolize a successful overcoming of pandemic times. Rather, they are an affective glimpse into a historical moment wherein labelled people struggle to stay in touch, resist social abandonment, navigate necropolitical ableism, and—through it all—leave evidence of their lives and what they are becoming in this time.¹⁹

Staying in Touch²⁰

1.

a lot of people feel
more isolated and lonely
since they can't hug anybody
I miss seeing people
being around people is important
you must have somebody with you
to understand you

I don't have the computer
I can't afford the internet
The only computer in the house
is in the staff office
we can't go to the library and use the computers
and internet to Google COVID-19
I can't go out and use a free computer

sometimes it's way different
sometimes it works
and sometimes it doesn't work
I don't think the virtual is the same thing
I never used it before
and it's been a big adjustment

2.

I live in a group home
I only get 25 minutes to go out
I can sit outside
but who wants to sit outside in the cold?
I have to shower when I come back
the staff don't want their kids to get sick

My family doctor
never calls me
all I know is that I got my doses
that's all that really matters
a vaccine is a vaccine, you know

either you know what you're talking about
or don't talk about it

I still take care of the animals
I cannot stand to clean the cat litter
but I'm going to have to do it
I wish COVID was over right now
do you wish that, too?

3.

I don't think that their response
has included people with disabilities
they intentionally don't care

Resisting social abandonment²¹

1.

I do talk on the phone
I would say talking on the phone is positive
I get some communication
we all deserve
to be alive
to belong

2.

I was still able to keep in touch
with people
so we were keeping
some form of contact
over the phone

3.

I miss going to the bank
and I need to do it
over the phone

I learn networking
that was a survival skill
because I could network
how to get things

he said to call
whenever
and I can phone her
if I need anything

4.

I think that isolation is worse
it's more unhealthy than anything else
that's what I believe.

I can't imagine.
I can't go out.
I want people.

COVID19 affects me.
We're still staying home.

5.

what's the government doing
for us?
it affects me
we have to do something about it
the government
has to do something about it

we can share it by talking about it

we call ourselves survivors

we're part of the community as well

call me
on the phone.

Past and Present Convergence²²

1.

It was kind of lonely

very eerie

it was creepy.

You would never usually see

Toronto like that

a ghost town.

2.

Some people with disabilities
have also experienced

so

much

trauma.

It's made my life

so

damn

hard.

It's the same thing like at the institution

I don't think about how I feel.

You have to live with it

and learn to be strong.

3.

It should've never happened.

The government
should have never

let it
happen.

4.

but everyone accepts what they have
they don't go out anyways
I've been living alone for 10 years

I sit by myself
I look for the single seat

I sit by myself
I stay home, I save lives.

I sit by myself
stay home

I sit by myself
save lives.

I sit by myself

That's what we have to do.

5.

We live in persecution
it's an infringement on our freedom

all the support workers tell us
that we are conspiracy theorists

Just be careful of your surroundings
Those who are more vulnerable

It always is harder because of their disabilities
it's hard to trust anybody

because of the way they treated us

in the past . . .

Becoming²³

1.

Doug Ford,²⁴ forget it
He's only for the rich people
the top brass
they keep turning up the heat
He doesn't give a damn
for the nursing homes
That Doug Ford,
the son of a gun,
he should tell people before it ever happens again

2.

things are changing because of the virus

*and it's a totally different way
everything's changed*

I'm sitting in the house all the time

*and it doesn't feel the same
at all*

it's changed a lot . . .

it's changed for everyone

3.

I don't think it's remained the same . . .
it's kind of in-between
positive and negative

except that it's been boring
it was kind of the same
and kind of not the same.

I was kind of getting used to it
and I was kind of not

it's just going to take a longer time
to jump back again.

4.

I just let things come and go
it's different than it was before
COVID is not finished yet
it depends where you live
I don't know if everybody
had the same experience
as me

5.

what I want to know is,
when it's going to end?
I just wish everything was open
and I hope they come out with the vaccine
this year if possible
they were too slow in responding
to the outbreak

6.

I don't know what to believe

I have been watching news
about vaccines and the numbers
going up and down
I can't understand

You should be able to believe

why they allow cannabis stores
where they blow smoke in the air
if they're so worried about germs

What you want to believe

You might end up calling me a conspiracy
theorist

they think there is a device in the vaccine
it's a bunch of baloney

And not what they tell you to believe

but there's not much
I can do about it
I just want the truth

7.

where's the housing they promised?

my worker, is she my parent?
she's not, right?

We have to stay for so long
until this is over, right?

I wish it was back to normal

it's gonna blow over.

I have air in my lungs.
the positive thing is that I'm still alive

that's all that matters

that's all that matters, right?

the answer to that is

I have no idea

8.

don't mind me
I'm mixing some psyllium and flax to add to
bread

look how it spoiled
our programs
what we were planning to do . . .
people with intellectual disabilities
need to be recognized

I still take care of the animals.
I still deliver papers on Thursday mornings
thank God I can be home to crochet and
knit
now I've got a mixture of flax seed and
psyllium

I try coping strategies the best I can
I can cope with changes.

for bread making!!

when I'm feeling down or something

I colour

You get to learn

things about yourself

that You maybe

didn't know

or things that You thought

You couldn't do

I get to talk about more of how I'm feeling

I get to share more

Everyone
is supposed to be

included

the world is changing too
things need to be changed.
that's up to God when I go . . .
not you . . .

and you're not taking my life
we all deserve to be alive

to belong . . .

I think one day it's going to change
understand *what we are going through*

I still think it should be
a choice

I wish people could stick together

I think we're better aware of it

education has to happen

take feedback

now!

she stood up for me

I'd like to see people

getting out of the house
going to the park
find your freedom
reconnect with your freedom

I have reconnected to my freedom

Notes

1. Christine Kelly and Michael Orsini, "Beyond Measure? Disability Art, Affect and Reimagining Visitor Experience," *Studies in Social Justice* 15, no. 2 (2021): 288–306, <https://doi.org/10.26522/ssj.v15i2.2432> < <https://doi.org/10.26522/ssj.v15i2.2432> > . ↩
2. Rosi Braidotti. "'We' Are in *This* Together, But We Are Not One and the Same," *Bioethical Inquiry* 17 (2020): 465–469, <https://doi.org/10.1007/s11673-020-10017-8> < <https://doi.org/10.1007/s11673-020-10017-8> > ↩
3. Adriana Van Altvorst, "Mia Mingus ~ Leaving Evidence" (Interview between Mia Mingus and Alice Wong, 2014), *Trauma Responsive New Zealand*, 2021, <https://www.pacesconnection.com/g/Trauma-responsive-New-Zealand/blog/mia-mingus-leaving-evidence> < <https://www.pacesconnection.com/g/Trauma-responsive-New-Zealand/blog/mia-mingus-leaving-evidence> > . ↩
4. The use of 'labelled/with' language reflects the heterogeneity that exists within the larger community of people identified by others or self-identifying as having an intellectual disability, making plain that while some people identify as having an intellectual disability, others resist this label and the ways it is imposed upon them. "Unlabelled" thus refers to people who have never had this label imposed upon them. ↩
5. Madeline Burghardt, *Broken: Institutions, Families, and the Construction of Intellectual Disability* (Montreal, QC: McGill-Queen's University Press, 2018); Nancy viva davis Halifax, David Fancy, Jen Rinaldi, Kate Rossiter, and Alex Tigchelaar, "Recounting Huronia Faithfully: Attenuating Our Methodology to the 'Fabulation' of Truths-Telling," *Cultural Studies, Critical Methodologies* 18, no. 3 (2018): 216–227; Kate Rossiter and Jennifer Rinaldi, *Institutional Violence and Disability: Punishing Conditions* (New York, NY: Routledge, 2019). ↩
6. Sandra L. Faulkner, *Poetic Inquiry: Craft, Method and Practice*, 2nd ed. (New York, NY: Routledge, 2020). ↩
7. Faulkner, *Poetic Inquiry*, 63, 70. ↩
8. Kakali Bhattacharya, "Voices Lost and Found: Using Found Poetry in Qualitative Research," in *Arts-Based Research in Education: Foundations for Practice*, edited by M. Cahnmann-Taylor and R. Siegesmund, Routledge, 2008, 83–88, cited in Sandra L. Faulkner, *Poetic Inquiry*, 2020, 64. ↩
9. Marjorie Perloff, "Found Poetry," in *The Princeton Encyclopedia of Poetry and Poetics*, Princeton University Press, 2012, 503–504; Monica Prendergast, "Found Poetry as Literature Review: Research Poems on Audience and Performance," *Qualitative inquiry* 12, no. 2 (2006): 369–388. ↩
10. Braidotti, "'We' Are in *This* Together," 466. ↩
11. Katie Fitzpatrick, "Writing the University Through Poetry: The Pleasure of Scholarship Against the Spike of Neoliberalism," in *Poetry, Method and Education Research: Doing Critical, Decolonising and Political Inquiry*, ed. Esther Fitzpatrick and Katie Fitzpatrick (New York: Taylor & Francis Group, 2021), 97–103. ↩
12. Adam Vincent, "Is There a Definition? Ruminating on Poetic Inquiry, Strawberries and the Continued Growth of the Field," *Art/Research International: A Transdisciplinary Journal* 3, no. 2

- (2018): 48–76. ↵
13. Braidotti, "'We' Are in *This* Together," 466. ↵
 14. Braidotti, "'We' Are in *This* Together," 465. ↵
 15. Shayda Kafai, *Crip Kinship: The Disability Justice & Art Activism of Sins Invalid* (Vancouver, BC: Arsenal Pulp Press, 2021). ↵
 16. Patty Berne, "Foreword," in *Crip Kinship: The Disability Justice & Art Activism of Sins Invalid*, ed. Shayda Kafai (Vancouver, BC: Arsenal Pulp Press, 2021), 10. ↵
 17. Accessible Canada, "Death by Coercion: A panel on the impacts of changes to medical assistance in dying on Black Queer Sick and Poor communities" (blog), February 1, 2021, <https://www.include-me.ca/making-canada-accessible/blog/2021/04/death-coercion> < <https://www.include-me.ca/making-canada-accessible/blog/2021/04/death-coercion>>. ↵
 18. Caryn Liberman, "Ontario's COVID-19 Triage Protocol 'Discriminates Because of Disability,' Advocates Say," *Global News*, April 28, 2021, <https://globalnews.ca/news/7816548/ontario-covid-triage-protocol-discriminates-disability-advocates/> < <https://globalnews.ca/news/7816548/ontario-covid-triage-protocol-discriminates-disability-advocates/>>. ↵
 19. Mia Mingus, *Leaving Evidence*, 2008, <https://leavingevidence.wordpress.com/about-2/> < <https://leavingevidence.wordpress.com/about-2/>>; Braidotti, "'We' Are in *This* Together," ↵
 20. While lockdowns impacted everyone, adults labelled/with intellectual disabilities, particularly those living in group homes or independent living settings operated by the provincial developmental service sector, experienced especially stringent and long-lasting isolation protocols and visitation bans. Contact with family members, friends, support workers and others has been, for many, almost non-existent. Engagement in day programs and employment was typically prohibited. Without appropriate supports, participation in adult education programs was made more difficult by the move to virtual education. Isolation was further exacerbated as many (including most of the labelled co-researchers) also lacked access to computer technology. ↵
 21. While recognizing how their experiences, support needs, and ideas are too often not considered, even by the broader disability community, during the pandemic, many people labelled/with intellectual disabilities understand themselves to be "the left behind of the left behind" (84). Staying connected, speaking out, networking become essential—necessary for survival. Ann Fudge Schormans, Sue Hutton, Marissa Blake, Kory Earle, and Kevin John Head., "Social Isolation Continued: Covid-19 Shines a Light on What Self-Advocates Know Too Well," *Qualitative Social Work* 20, no. 1–2 (2021): 83–89. ↵
 22. The power and tenacity of the legacy of institutionalization was readily apparent in the impact of pandemic isolation protocols on group members labelled/with intellectual disabilities and labelled people as a group, particularly those living in developmental service residential placements. For survivors, isolation and feelings of abandonment during the pandemic were reminiscent of past experiences of institutionalization. For younger members, they were a painful reminder of ongoing experiences of exclusion and social devaluation common to many people labelled/with intellectual disabilities. ↵
 23. Without exception, labelled group members want the pandemic to end. Throughout they have experienced what Braidotti describes as "complex and internally contradictory alternation of emotions. . . . An intense sense of suffering alternating with hope, fear unfolding alongside resilience, boredom merging into vulnerability" (465), and this is reflected in this poem. While desiring an end to the pandemic, they have also made plain that "a return to 'normal' is to be resisted—'normal' has not worked in the past, has proven harmful, and will not be any better in the future" (Fudge Schormans, et al. "Social Isolation Continued," 88). Recognizing the pandemic's disruptive impact on the world, on "normal" ways of being and doing, their own lives and sense of themselves, they also point to how, if recognized as such by non-labelled others, this moment is an opportunity for things to change for the better for people labelled/with intellectual disabilities. ↵

24. Doug Ford is, at the time of this writing, the premier of the province of Ontario, Canada where the "DiStory" project members live, and thus bears some responsibility for the policies and practices enacted during the pandemic. ↩

Author Information

Erin Kuri

Erin Kuri is a PhD candidate in the School of Social Work and a PhD student in the Department of Gender Studies and Feminist Research. She has over a decade of clinical experience as an advocate and psychotherapist specializing in art therapy and trauma, primarily working in the areas of child welfare, gender-based violence, and maternal and infant mental health. Erin draws on interdisciplinary feminisms, ethics, critical disability studies, motherhood studies, and trauma theory to develop collaborative and arts-based approaches to knowledge building. Her SSHRC-funded doctoral research explores how young mothers make meaning of the concept of support within the context of service provision.

[View all of Erin Kuri's articles.](#)

Antoinette

I am a friendly person. I volunteer and visit with people. Under COVID, I can't do that anymore, so I crochet blankets at home to give to people. I am doing this project because I want people to know our story and what happened to us. I think it's good that we're telling our stories. I think it's good to let people hear what happened to everybody in their life. You have to be nice to everybody. It's the way you feel in your heart, to give it back.

[View all of Antoinette's articles.](#)

A. K.

A.K. completed a two-year program at North Humber College. He is currently employed with a courier company called A-Way Express. A.K. is an avid biography reader. He lives in an apartment in downtown Toronto, Ontario.

[View all of A. K.'s articles.](#)

Bill Chase

I am a survivor of physical, mental, and psychological abuse that I experienced during my years in the Huronia Regional Centre. I am doing this project because I am a former patient at Huronia, which used to be the Ontario School of Orillia

in the 1950s. I want to let people know what former patients had to go through during their years in this institution. People need to know what everyone had to go through during their time growing up inside of an institution. I want there to be a better understanding of it.

[View all of Bill Chase's articles.](#)

Cindy Scott

Cindy Scott is a survivor of Huronia Regional Centre, and a strong advocate for survivors. She is actively involved in Remember Every Name and their work to make sure the names of people buried at Huronia in unmarked graves become known.

[View all of Cindy Scott's articles.](#)

Doreen Kalifer

I am person that believes in justice and fairness. I believe that people are special in their own way. I like being part of the DiStory group because I fight for the justice of people not being bullied because they are different. I want people to have a better understanding of people with disabilities and for people described as different to have better rights, and for more knowledge spread out to the universe about these things. I write poetry about justice and bullying because this has always been a cause for me.

[View all of Doreen Kalifer's articles.](#)

Harold George Dougall

I am a survivor of the Huronia Regional Centre. I am 74 years old. I am living in a community in Simcoe North, Ontario, Canada. I am living on my own. I have a cat. I am interested in being involved in politics in my community. I like to teach people about the history of what I went through.

[View all of Harold George Dougall's articles.](#)

Kevin John Head

Kevin John Head is a self-advocate who recognizes the importance of educating non-disabled people in order to work towards change. Kevin has been a co-researcher on a number of projects. He believes it is important to

share information about these projects with different audiences, in different ways.

[View all of Kevin John Head's articles.](#)

Marie

I am a human being with rights. I am doing this project because I want people to know that what they did in the institution was wrong, so that they won't do it again. I would like to see changes made so that people with disabilities are more respected, listened to, and believed.

[View all of Marie's articles.](#)

Nicholas Herd

I am an actor, performer, and talk show host. I want to see the whole world know about people with disabilities and their stories. I am doing this project so that people can understand how everyone is different. Some of us are advocates fighting for people with other disabilities. I want to see people think about how we can shape our world, where everybody can belong, and each of us is part of all of us. I want people to learn how we can contribute from many different parts of who we are and how we can express ourselves in different ways. Everybody is different and we need to celebrate difference.

[View all of Nicholas Herd's articles.](#)

P. A. I.

She would like to one day go to college to learn how to work with children with disabilities.

[View all of P. A. I.'s articles.](#)

P. S.

[View all of P. S.'s articles.](#)

R.

[View all of R.'s articles.](#)

Sean Simone

I live in a group home in a city. My parents got an Order of Canada. I have been working with the DiStory group.

[View all of Sean Simone's articles.](#)

Chelsea Temple Jones

Chelsea Temple Jones is an Assistant Professor in the Department of Child and Youth Studies, Brock University. A queer, white settler spoonie, Dr. Jones holds a Ph.D. in Communication and Culture from X and York Universities and an MA in Critical Disability Studies from York University. She completed a Mitacs postdoctoral fellowship at the University of Regina's Vocally Oriented Investigations of Create Expression (VOICE) Lab—a studio space for disabled folx who communicate in various ways, and not always through speech. A member of the DiStory project, she also holds a SSHRC Insight Development Grant that continues her study of the ways in which ableist, colonial gestures of "giving voice" face resistance from young, disabled adults engaged in disability justice.

[View all of Chelsea Temple Jones's articles.](#)

[Ann Fudge Schormans](#)

Ann Fudge Schormans is a Professor in the School of Social Work at McMaster University. A white, cisgender settler, Dr. Fudge Schormans' long history of engagement with people labeled/with intellectual disabilities through social work practice and research, combined with ongoing activist work informs her teaching and research. Employing inclusive, co-researcher methodologies and knowledge production, arts-informed methods, and writing with disabled co-researchers current research projects include the DiStory project that is co-developing curriculum materials for post-secondary education with survivors of Ontario's institutions and younger generations of people labeled/with intellectual disability; Partnering for Change, which attends to the intersection of disability and youth homelessness; Mobilizing Critical Disability Studies

(CDS) Scholarship in non-CDS Spaces; and projects focused on intimate citizenship for people labeled/with intellectual disabilities.

[View all of Ann Fudge Schormans's articles.](#)

Article details

Erin Kuri, Antoinette, A.K., Bill Chase, Cindy Scott, Doreen Kalifer, Harold George Dougall, Kevin John Head, Marie, Nicholas Herd, P.A.I., P.S., R., S.S., Chelsea Temple Jones and Ann Fudge Schormans, "Coalition-In-Progress: Found Poetry Through Phone Calls with People Labelled/With Intellectual Disability During the COVID-19 Pandemic," *Lateral* 11.2 (2022).

<https://doi.org/10.25158/L11.2.9>

This article is licensed under a [Creative Commons Attribution-NonCommercial 4.0 International License](#). Copyright is retained by authors.

Lateral is the peer-reviewed, open access journal of the [Cultural Studies Association](#).

ISSN 2469-4053